

## **Sharing your story to promote living donation**

Real-life stories from both the perspective of someone who has donated an organ during their lifetime and from someone who has benefitted from a living donor transplant can be extremely powerful. Your story could help educate, inform and inspire people to consider becoming living organ donors.

### **Sharing your living donation story in the media**

The media is a great way to get your story out there and to promote living donation. If you're a living donor who has donated to someone you don't know, we would recommend you seek advice from your living donor coordinator before sharing details with the media. If you've received a kidney or part of a liver from a stranger we would recommend you seek advice from your transplant coordinator. This helps protect everyone's privacy - if you give specific information on dates and transplant units, you could accidentally identify other people involved, such as the other recipients or donors.

In our experience, journalists treat people sharing their story about donation very respectfully and stories about living donation help encourage more people to support both living and deceased donation. Bear in mind that ultimately it is a journalist or editor's decision whether they choose to cover your story or not and they should be able to let you know quite quickly whether this is something they are interested in or not. It's unlikely that a journalist will cover your story anonymously, they will probably want to use your name and photos. A journalist will write up your story in their own words in the style of their newspaper or magazine. They may sometimes give you the chance to read or listen back to the article before publication – that is something you should clarify with them in advance. If you are sharing your story with a journalist, once it's published it could appear in other publications or anywhere online. If a journalist asks you something too personal, explain that you would prefer not to answer the question. If you need more guidance, or if there are difficult or sensitive areas you are unsure about, speak to your living donor coordinator or the NHS Blood and Transplant press office ([pressoffice@nhsbt.nhs.uk](mailto:pressoffice@nhsbt.nhs.uk)).

*Many people tell us that they enjoy helping to promote donation through the media. So hopefully you will too!*

You can approach TV, radio, or print, whatever you feel is right for you.

- Call or email their news desk with a simple summary of your story straightaway so you can gauge their interest.
- They'll probably want to get more details, your name, age, hometown, family details, why you volunteered to donate / why you needed a transplant etc.
- If they are interested in covering your story they'll want to do an interview and perhaps interview you on camera or take photos. They will ask you questions about your story and it will just be for you to tell them in your own words about what happened
- If your story involves someone else – a relative or friend – they may want to include details about them and possibly interview them and include film footage or photos of them too. So, check they're happy with you sharing your story before you do so.

- If you did not know the person you donated to / received a transplant from, please avoid giving the exact date of your donation – a month and year is the most detail we recommend. This will help ensure that they don't find out about you if they are not ready to do so. In this situation, it is better to approach the media about publicity after you have donated/received a transplant rather than before the operations so that there is no risk of inadvertently identifying anyone involved beforehand.
- Before being accepted as a living donor, patients are stringently assessed to minimize the risks. It would be great if you can make sure you explain how you were assessed and how any risks were explained to you. You can also direct them to our website for further information about this [www.organdonation.nhs.uk/livingdonation](http://www.organdonation.nhs.uk/livingdonation).
- If the media you approached aren't interested in covering your story, don't be disheartened. There are other things you can do to help promote donation – your local hospital may hold awareness raising events, you can share your story on social media, you could give a talk to a local group or school or you could write a letter to your local paper and see if they'll print that instead. You could contact the 'Give a Kidney' charity at [www.giveakidney.org](http://www.giveakidney.org) who are always looking for people who are willing to support the work they do in raising awareness about living donor kidney transplantation.

### Sharing your living donation story on social media

Sharing your living donation story on social media is a great way to raise awareness of living donation. If you are a living donor who has donated to someone you don't know or someone who has benefitted from living organ donation and you would like to share your story on social media, we would recommend you seek advice from your living donor coordinator / transplant coordinator before sharing any details. This helps protect everyone's privacy - if you give specific information on dates and transplant units, you could accidentally identify other people involved, such as the other recipients or donors.

Here are a few things you may want to think about first: -

- The content you place on social media can become widely shared and lead directly to people signing up to donate.
- While you can control the wording of what you initially post, you cannot control the comments that others may make or how widely people will share your story. Don't let this put you off, as personal stories tend to generate very positive comments.
- If you did not know the person you donated to / received a transplant from, please avoid giving the exact date of your donation – a month and year is the most detail we recommend. This will help ensure that they don't find out about you if they are not ready to do so. Avoid posting details on social media that could identify any of the donors and recipients involved before the operations have taken place and think carefully about any information that you post on the day of donation/transplant- this can inadvertently identify other people involved.
- If you donated/received a transplant from a stranger, avoid stating this within your post for anonymity reasons.
- If your story involves someone else – a relative or friend – check they're happy with you sharing your story before you do so.

Here are some tips to make your social posts engaging: -

- Keep your post simple and try not to include too much medical terminology – people are often more interested feelings and emotions rather than factual information.
- Use photos to link in with your story. Be sensitive to other people’s individual circumstances.
- Keep language conversational rather than formal and don’t worry about writing in a traditional or chronological style, for example, it’s ok to start your post with ‘My life was transformed by a donor’ than ‘I first noticed symptoms x years ago.’
- Include a clear call to action, an example of this could be ‘Find out more about living donation visit [www.organdonation.nhs.uk/livingdonation](http://www.organdonation.nhs.uk/livingdonation).’
- Include a popular hashtag within your post(s) – for example #YesIDonate, #ShareYourSpare #organdonation #organdonor #livingdonation.
- Tag @NHSOrganDonor in your posts so we can share them on our own social media pages.
- You might want to reply to questions or speak to people who are in a similar situation to you. We recommend you check your privacy settings on your social media accounts and don’t share any personal information such as your email address publicly.
- Posting a ‘seeking a kidney’ message - You may have seen people posting their stories on social media because they are waiting for a transplant and hope that someone may offer to donate to them. This is complicated because it is very unlikely that someone who offers to donate to you would be able to do so, specifically to you. If you are thinking about posting your story, please speak to the doctors and nurses in your transplant team first so that they can advise you and talk to you about the best way to approach this.

Thank you for your support!

**NHS Blood and Transplant**  
**Media and PR Teamd**